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Which patients are assessed by lung cancer nurse specialists? A national lung cancer audit study of over 128,000 patients across england

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ABSTRACT

Background: Lung cancer nurse specialists (LCNS) are integral to the multidisciplinary clinical team, providing personalised physical and psycho-social interventions, and care management for people with lung cancer. The National Institute of Health and Care Excellence (NICE) recommend that all patients have access to a LCNS. We conducted a national study assessing whether there is variation in access to and timing of LCNS assessment.
Methods: The National Cancer Action Team's LCNS workforce census in England was linked with patient and hospital Trust data from the English National Lung Cancer Audit. Multivariate logistic regression was used to assess features associated with LCNS assessment.
Results: 128,124 lung cancer patients were seen from 2007 to 2011. LCNS assessment confirmation was 'yes' in 62%, 'no' in 6% and 'missing' in 32%. Where (in clinic versus ward) and when (before versus after diagnosis) patients were assessed by a LCNS also varied. Older patients with poor performance status, early cancer stage, and comorbidities were less likely to be assessed; there was no difference with sex or socioeconomic group. Patients receiving any anti-cancer treatment were more likely to be assessed. Assessment was lower in Trusts with high annual patient numbers (odds ratio = 0.58, 95% confidence interval 0.37–0.91) and where LCNS caseload > 250 (0.69, 0.41–1.16, although not statistically significant), but increased where workload was conducted mostly by band 8 nurses (2.22, 1.22–4.02).
Conclusion: LCNS assessment varied by patient and Trust features, which may indicate unmet need for some patients. The current workforce needs to expand as well as retain experienced LCNSs.

1. Introduction

Lung cancer (LC) is the second most common cancer in the United Kingdom (UK) with 39,000 new cases annually in England [1,2]. Recent National Institute for Health and Care Excellence (NICE) guidelines recommend that every person diagnosed with LC has direct personal access to a Lung Cancer Nurse Specialist (LCNS) in their local hospital who they can meet with and be supported by throughout the cancer pathway [1,3]. LCNSs are now integral to the multidisciplinary team (MDT) within which they contribute to decisions on their patients' treatment and care [4]. Previous research has shown the effectiveness of tailored nursing care and proactive LCNS case management in reducing unnecessary hospital admissions and doctor consultations, symptom control, emotional functioning and patient-reported satisfaction for early and metastatic LC [5–8]. A 2002 randomised control trial by Moore and colleagues of 203 patients showed that LCNS led follow-up was also cost-effective when compared with conventional medical follow-up [8].

Although LC is the second commonest cancer in the UK [9], LCNSs comprise only 11% of the Cancer Nurse Specialists (CNSs) in England, compared with breast (20%), colorectal (14%) and urol-

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ogy (12%) CNSs [10]. A recent Macmillan report highlighted that on average, there is one LCNS for every 161 people diagnosed with LC, compared with 117 people diagnosed with breast cancer [11]. According to the 2013 National Lung Cancer Audit (NLCA) annual report, approximately 80% of all patients are now assessed by a LCNS, but there is variation by Trust and only 30% of LC patients are assessed in some Trusts [12].

In this study we linked individual clinical information from the NLCA, the English Hospital Episode Statistics (HES) and Office of National Statistics (ONS) deaths with the National Cancer Action Team (NCAT) census on the LCNS workforce. We assessed whether, when and where patients are assessed by a LCNS and how clinical, demographic, socioeconomic status (SES) of patients and National Health Services (NHS) Trust characteristics including Trust size, LCNS salary bands and caseload affected their assessment.

2. Methods

The NLCA collects key clinical information on all new patients presenting with a diagnosis of LC in the UK. In this study data from the NLCA was linked with HES, which includes all inpatient admissions in England, ONS mortality data to provide nationally registered dates of death, and NCAT, a census of the entire cancer specialist nurse workforce in England which provided details on the LCNS workforce.

We included all patients in the NLCA who were first seen in England between January 1st, 2007 and December 31st, 2011 across 150 NHS Trusts in England. We used the latest NCAT census carried out in 2011 to map the workforce of 321 LCNS to NHS Trusts. Trusts without LCNS workforce information from the NCAT (n = 4) were dropped leaving 146 Trusts for analysis. Patients diagnosed with LC through death certificate and those with mesothelioma or carcinoid were excluded.

The NLCA records whether the patient is assessed by a LCNS (*yes*, *no*), date of assessment, timing of assessment in the cancer pathway and location of the first assessment. We categorised the timing of assessment as *before/at diagnosis* versus *after diagnosis* and the location of assessment as *in clinic* versus *ward* or *other location* (*i.e. home visit, telephone or other*). For each of the three variables, where no information was entered they were separately categorised as missing.

Age at diagnosis, sex, SES, source of referral to a LC physician, performance status (classified according to WHO definition) and stage of disease (Union for International Cancer Control definition) were identified from NLCA. Data on active treatment were obtained from a combination of the NLCA and HES using methods as previously described in Ref. [13–15] and categorised as no treatment, surgery, chemotherapy and radiotherapy, chemotherapy alone or radiotherapy alone. We used HES to calculate a patient's composite score of co-morbidity (Charlson Index).

We used the NLCA to calculate the number of new LC patients seen annually in each Trust using our established methods [14]. We estimated each Trust's caseload per whole time equivalent (WTE) LCNS using the number of new cases first seen in 2011 plus the number of patients surviving since 2004, divided by the number of WTE LCNSs employed at the Trust. We assumed that the patients initially seen in a particular Trust were equally divided between the LCNSs employed by that Trust and that patients followed the LC pathway in that same Trust. Using NCAT information on salary bands of WTE LCNSs, we assessed the composition of the LCNS team at each trust. We also estimated which LCNS salary band conducted the majority of the work based on WTE employment at each Trust (e.g. Trust A was categorised at Band 7 if more than 50% of the total WTE LCNSs were on salary band 7).

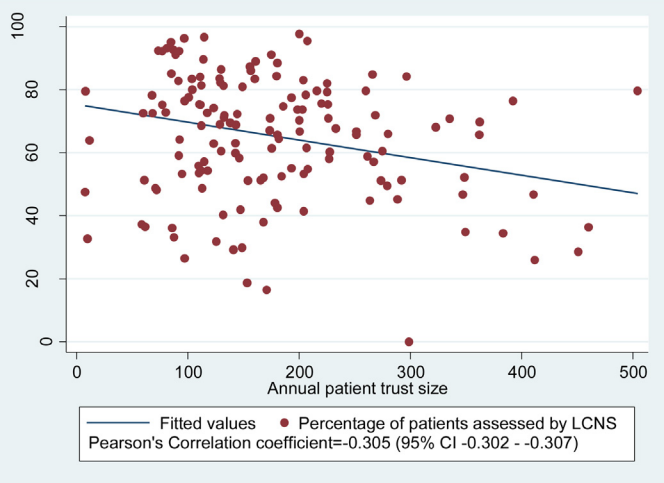

Fig. 1. Percentage of patients with LCNS assessment by Trust size (annual number of new lung cancer patients).

2.1. Statistical analysis

All data analyses were performed using Stata MP12. Initially we plotted the percentage of patients recorded as having been assessed by a LCNS by the Trust size (average number of patients seen annually) and calculated the Pearson's correlation coefficient to quantify the relationship. We used multinomial logistic regression analyses, to estimate the relative risk ratio (RRRs) of being assessed by a LCNS by patient and NHS Trust features. For all patients who had information on having been assessed, we also performed separate analyses to estimate the RRRs of being assessed after diagnosis versus before/at diagnosis and being assessed in clinic versus being assessed on wards. The unadjusted and adjusted RRR were clustered by NHS Trust to account for the hierarchical grouping of patient observations. A separate analysis was carried out for patients with missing data and a sensitivity analyses was conducted excluding all patients who died within 30 days of diagnosis to account for immortal time bias.

3. Results

There were a total of 128,124 people with LC who were first seen between 1 January 2007 and 31 December 2011, of whom 80,113 (63%) were seen by a LCNS, 7544 (6%) were not seen and 40,467 (31%) had missing data. The proportion of patients assessed increased over the study period (6216 (31%) in 2007-23,045 (80%) in 2011), mainly driven by a decrease in the missing data. From those who were assessed, 3809 (5%) had missing information on the timing of first assessment and 8317 (10%) on the location. We observed a borderline moderate negative correlation between the number of new cases seen at a Trust and the proportion of patients assessed by a LCNS (Fig. 1 Pearson's correlation coefficient = −0.305).

3.1. Who is assessed by LCNS

Table 1 shows results for being assessed by a LCNS by patient features. The RRR of being assessed by a LCNS was 6% higher for men compared with women, but this association was accounted for when we adjusted for other patient features and Trust/LCNS features (RRR 1.02, 95% CI 0.96–1.07). There was a clear association seen with age with patients > 75 years less likely to be assessed. Patients with worse performance status (PS) and with comorbidities were also less likely to have been assessed. Patients with LC stage other than stage IA–IB and stage IV had a higher RRR of being

assessed by a LCNS. The association with stage IV patients was not seen when we carried out a sensitivity analysis and restricted our analyses to patients who survived more than 30-days after diagnosis (Supplemental Table 1).There was no difference by SES. We analysed missing data separately and that the RRR of missing data compared with patients not assessed revealed that there was no dif-

Table 1
Multinomial logistic regression analysis for patient features and likelihood of being assessed by a LCNS clustered by NHS Trusts (n = 128,124).

	LCNS Assessed						Adjusted Relative risk ratio[a]
	No n = (7544)	%	Yes n = (80113)	%	Missing n = (40467)	%	Yes vs No
Year							
2007	675	9	6216	8	13,041	32	1
2008	1368	18	12,235	15	10,593	26	0.98 (0.69–1.40)
2009	1618	21	17,676	22	8217	20	1.17 (0.80–1.72)
2010	2059	27	20,941	26	4695	12	1.10 (0.71–1.70)
2011	1824	24	23,045	29	3921	10	1.33 (0.86–2.05)
Sex							
Female	3437	46	35,269	44	17,428	43	1
Male	4107	54	44,844	56	23,039	57	1.02 (0.96–1.07)
Age							
<65	1325	18	21,715	27	10,346	26	1[b]
65–75	1961	26	27,118	34	12,804	32	1.05 (0.96–1.14)
>75	4258	56	31,280	39	17,317	43	0.84 (0.75–0.93)
Performance status							
0	590	8	14,318	18	4994	12	1[b]
1	1012	13	24,737	31	7208	18	1.14 (0.92–1.41)
2	1105	15	15,441	19	4802	12	0.97 (0.77–1.23)
3	2038	27	12,254	15	4903	12	0.63 (0.48–0.81)
4	1220	16	3098	4	2038	5	0.34 (0.24–0.46)
Missing	1579	21	10,265	13	16,522	41	0.47 (0.34–0.65)
Stage							
IA-IB	716	10	8779	11	3528	9	1[b]
IIA-IIB	267	4	4692	6	1567	4	1.42 (1.18–1.71)
IIIA	448	6	7590	9	2352	6	1.35 (1.16–1.57)
IIIB	635	8	9322	12	3739	9	1.28 (1.09–1.49)
IV	3295	44	29,479	37	11,191	28	1.10 (0.96–1.27)
SCLC-Limited	99	1	2933	4	845	2	1.48 (1.17–1.88)
SCLC-Extensive	402	5	5792	7	1849	5	1.25 (1.05–1.49)
Stage Unknown	1682	22	11,526	14	15,396	38	0.89 (0.72–1.09)
Charlson Index							
0	1493	20	26,132	33	13,206	33	1[b]
1	1237	16	16,162	20	7711	19	0.95 (0.86–1.04)
2–3	1386	18	13,892	17	6938	17	0.86 (0.78–0.94)
4+	3428	45	23,927	30	12,612	31	0.71 (0.64–0.80)
Townsend Quintile							
1 (Most affluent)	1046	14	12,253	15	6509	16	1
2	1417	19	14,506	18	7785	19	0.89 (0.81–0.99)
3	1463	19	15,670	20	7977	20	1.00 (0.90–1.11)
4	1570	21	16,978	21	8639	21	1.04 (0.91–1.20)
5 (Least affluent)	1824	24	19,240	24	9121	23	1.06 (0.87–1.29)
Missing	224	3	1466	2	436	1	0.88 (0.68–1.12)
Route of referral							
Referred from GP	2205	29	40,409	50	17,590	43	1[b]
Emergency Admission	2021	27	9468	12	4889	12	0.43 (0.35–0.53)
Referred from Consultant	1585	21	16,553	21	8150	20	0.74 (0.63–0.86)
Following A&E admission	804	11	5310	7	3027	7	0.62 (0.48 – 0.82)
Others	425	6	5306	7	3492	9	0.87 (0.64 – 1.19)
Missing	504	7	3067	4	3319	8	0.46 (0.25 – 0.87)
Treatment							
No treatment	5349	71	27,205	34	18,400	45	1[b]
Surgery	603	8	11,615	15	5605	14	2.04 (1.71–2.44)
Chemo & radiotherapy	255	3	9626	12	2578	6	3.93 (3.10–4.98)
Chemo Only	543	7	17,091	21	7828	19	3.42 (2.67–4.38)
Radiotherapy only	794	11	14,576	18	6056	15	2.57 (2.18–3.04)
Trust Size (Annual)							
<175 pts	2351	31	30,765	38	13,503	33	1[b]
> = 175 – <265 pts	2195	29	26,507	33	10,165	25	0.97 (0.64–1.49)
> = 265 pts	2998	40	22,841	29	16,799	42	0.58 (0.37–0.91)
Caseload							
< = 150 cases	1648	22	18,673	23	6509	16	1
>150 – < = 250 cases	3672	49	43,497	54	24,783	61	1.08 (0.69–1.69)
> 250 cases	2224	29	17,943	22	9175	23	0.69 (0.41–1.16)

Table 1 (*Continued*)

	LCNS Assessed						Adjusted Relative risk ratio[a]
	No n = (7544)	%	Yes n = (80113)	%	Missing n = (40467)	%	Yes vs No
LCNS dealing with >50% work[c]							
Majority work 7 band	5986	79	66,942	84	34,746	86	1
Majority work 6 band	1466	19	10,370	13	5069	13	0.71 (0.47–1.07)
Majority work 8 band	92	1	2801	4	652	2	2.22 (1.22–4.02)
LCNS Band[c]							
All 7 band	3404	45	35,513	44	16,989	42	1
6,7 & 8 Bands	3619	48	35,808	45	20,347	50	0.96 (0.63–1.45)
7,8 Bands	521	7	8792	11	3131	8	1.59 (0.86–2.92)

Baseline group patients not assessed by LCNS.

[a] Relative risk ratio adjusted for Trust/LCNS feature, year and patient features.

[b] Significant p value for trends/likelihood ratio test ($p < 0.05$).

[c] Not Adjusted for other LCNS Band Variable.

ference in being recorded as not seen between patients with stage IA-IB and stage IV. The amount of missing data was similar between patients from different SES (Supplemental Table 2).

Patients admitted through an emergency route were 57% less likely to have been assessed compared with those who were referred by a GP. Active treatment was also associated with assessment. Patients who had surgery were twice as likely to be assessed (RRR 2.04), while patients who receive chemotherapy alone or radiotherapy alone were three times as likely to be assessed (RRR 3.42 & 2.51 respectively). However, the strongest association was seen in patients who receive chemotherapy and radiotherapy, who were four times as likely to be assessed (RRR 3.93, 95% CI 3.10–4.98). This association was also present in patients surviving more than 30-days post diagnosis.

Patients first seen in a Trust with an annual LC caseload of > = 265 patients were less likely to be assessed compared with smaller Trusts (adjusted RRR 0.58), but we found no association with increasing annual LCNS caseload. There was a higher likelihood of being assessed in Trust where the LCNS were on salary band 7 or 8 (RRR 1.59), however clustering by NHS Trusts widened the confidence interval and made the association non-significant. Patients first seen in Trusts where the majority of work was done by band 8 nurses were twice as likely to have been assessed compared 7 band Trusts (RRR 2.22, 95% CI 1.22–4.02), while trusts where majority of work is done by a band 6 LCNS were less likely to have been assessed (RRR 0.71, 95% CI 0.47–1.07).

3.2. Point of lung cancer pathway where the patient is first assessed

Table 2 shows results for the point at which the patient was first assessed by a LCNS (n = 80,113). Patients with age > 75 years, worsening PS and stage, other than stage IV, were less likely to be assessed before/at diagnosis but we found no difference with sex. Patients with a comorbidity score of higher than 4 were slightly more likely to be assessed before diagnosis than after diagnosis, while there was no difference with SES. Patients admitted through emergency were less likely to have been assessed before diagnosis; however those who were referred from another consultant were 76% more likely to have been assessed before receiving their lung cancer diagnosis. Patients having surgical treatment were almost twice more likely to have been assessed before/at diagnosis than after diagnosis while significant association for patients receiving chemotherapy and radiotherapy was only present in patients surviving 30-days post LC diagnosis (Supplemental Table 1). There was no association seen with the likelihood of being assessed before/at diagnosis than after diagnosis with either increasing annual trust size or annual WTE LCNS caseload. LCNS on salary grade 7 or 8 were more likely to assess a patient before/at diagnosis than LCNS on a lower salary grade while there was no association seen with trusts were majority of work is done by either band 6, 7 or 8.

3.3. Where the patient is first assessed?

Table 3 presents an overview of unadjusted and adjusted RRR of where the patients are first assessed by a LCNS. Over the years, the proportion of patients being assessed in clinics versus the proportion being assessed in wards has remained the same. Males and young people were 9% less likely to have been first assessed in a ward than in a clinic. The strongest association was seen with PS. Patients with PS 4 were almost 7 times more likely to have been first seen in a ward than in clinic. People with advanced stage and comorbidity were also associated with patients being more likely to have been first assessed in the ward. There was no difference in where the patient is first seen by SES, increasing annual WTE LCNS caseload or LCNS salary grade/majority work. Patients who receive any treatment are less likely to have their first assessment by a LCNS in wards than in clinic (RRR 0.48 surgery, 0.47 chemotherapy and radiotherapy, 0.51 chemotherapy alone and 0.64 radiotherapy alone).

4. Discussion

Our results demonstrate an increase in the absolute proportion of patients assessed in recent years which is mainly driven by improvements in data completeness. However, the data reveals that older patients, with poorer PS, and those admitted through an emergency route are less likely to be assessed, which was still present in patients surviving more than 30-days after diagnosis, highlighting unmet need. However, it is possible that some patients are appropriately being referred to supportive and palliative care nurses, and that the LCNS is instrumental in making this happen. In contrast to research which indicates a more active approach to treatment in larger Trust, we found borderline moderate negative association between assessment and Trust size.

Overall 32% of patients in our data had missing data. Even though the ascertainment of this information has improved in recent years, our results may be an underestimate of the true proportion of patients assessed by a LCNS.

As reported previously, there is a strong association between assessment by a LCNS and active anticancer treatment [4]. We observed a higher likelihood of being assessed before diagnosis by a LCNS on a higher salary grade (i.e. 7 or 8) and a higher likelihood of being assessed where majority of work is done by band 8 nurses. This may be linked to a better leadership qualities and an active involvement in MDT clinics by senior nurses. While patients diagnosed in a Trust with an annual Trust size of > 265 were less likely to have been assessed, the effect of increasing caseload per

Table 2
Multinomial logistic regression analysis for patient features and at what point in the lung cancer pathway was the patient assessed clustered by NHS Trusts (n = 80,113).

	At what point was patient assessed (n = 80,113)						Adjusted Relative risk ratio[a]
	After diagnosis n = (34149)	%	Before/at diagnosis n = (42155)	%	Missing n = (3809)	%	Before/at diagnosis vs After diagnosis
Year							
2007	2345	7	3047	7	824	22	1[b]
2008	4977	15	5861	14	1397	37	0.87 (0.69–1.11)
2009	7968	23	9071	22	637	17	0.83 (0.63–1.08)
2010	9180	27	11,167	26	594	16	0.87 (0.66–1.16)
2011	9679	28	13,009	31	357	9	0.94 (0.71–1.24)
Sex							
Female	14,963	44	18,678	44	1628	43	1
Male	19,186	56	23,477	56	2181	57	0.97 (0.95–1.00)
Age							
<65	8801	26	11,869	28	1045	27	1
65–75	11,265	33	14,584	35	1269	33	0.98 (0.93–1.02)
>75	14,083	41	15,702	37	1495	39	0.93 (0.88–0.98)
Performance status							
0	5236	15	8391	20	691	18	1[b]
1	9991	29	13,951	33	795	21	0.97 (0.85–1.10)
2	6713	20	8203	19	525	14	0.93 (0.79–1.09)
3	5904	17	5957	14	393	10	0.83 (0.69–1.01)
4	1524	4	1460	3	114	3	0.83 (0.65–1.07)
Missing	4781	14	4193	10	1291	34	0.68 (0.56–0.82)
Stage							
IA-IB	3103	9	5308	13	368	10	1[b]
IIA-IIB	1811	5	2705	6	176	5	0.90 (0.83–0.97)
IIIA	3058	9	4250	10	282	7	0.94 (0.88–1.01)
IIIB	4063	12	4857	12	402	11	0.88 (0.80–0.96)
IV	13,409	39	14,987	36	1083	28	0.84 (0.78–0.90)
SCLC-Limited	1161	3	1692	4	80	2	1.00 (0.90–1.12)
SCLC-Extensive	2496	7	3142	7	154	4	0.91 (0.81–1.02)
Stage Unknown	5048	15	5214	12	1264	33	0.81 (0.71–0.92)
Charlson Index							
0	11,281	33	13,586	32	1265	33	1[b]
1	6799	20	8591	20	772	20	1.09 (1.03–1.15)
2–3	5997	18	7253	17	642	17	1.09 (1.03–1.16)
4+	10,072	29	12,725	30	1130	30	1.31 (1.22–1.41)
Townsend Quintile							
1 (Most affluent)	5379	16	6296	15	578	15	1
2	6369	19	7534	18	603	16	1.01 (0.93–1.11)
3	6780	20	8237	20	653	17	1.04 (0.94–1.15)
4	7204	21	8919	21	855	22	1.06 (0.93–1.20)
5 (Least affluent)	7729	23	10,428	25	1083	28	1.20 (1.00–1.43)
Missing	688	2	741	2	37	1	1.07 (0.90–1.29)
Route of Referral							
Referred from GP	15,995	47	22,678	54	1736	46	1[b]
Emergency Admission	4910	14	4144	10	414	11	0.61 (0.52–0.71)
Referred from Consultant	7389	21	8522	20	642	17	0.76 (0.67–0.87)
Following A&E admission	2779	8	2216	5	315	8	0.57 (0.49–0.68)
Others	1954	6	3028	7	324	9	1.11 (0.79 – 1.56)
Missing	1122	3	1567	4	378	10	1.01 (0.73 – 1.38)
Treatment							
No treatment	12,801	37	12,906	31	1498	39	1[b]
Surgery	3565	10	7401	18	649	17	1.74 (1.54–1.96)
Chemo & radiotherapy	4119	12	5222	12	285	7	1.10 (0.95–1.27)
Chemo Only	7203	21	9126	22	762	20	1.12 (1.03–1.22)
Radiotherapy only	6461	19	7500	18	615	16	1.07 (0.98–1.17)
Trust Size (Annual)							
<175 pts	13,240	39	16,461	39	1064	28	1[b]
> = 175 – <265 pts	10,849	32	14,072	33	1586	42	1.02 (0.67–1.55)
> = 265 pts	10,060	29	11,622	28	1159	30	0.85 (0.58–1.23)
Caseload							
< = 150 cases	7860	23	10,450	25	363	10	1
>150 – < = 250 cases	18,637	55	22,109	52	2751	72	0.92 (0.58–1.45)
>250 cases	7652	22	9596	23	695	18	1.02 (0.60–1.73)
LCNS dealing with >50% work[c]							
Majority work 7 band	29,245	86	35,128	83	2569	67	1
Majority work 6 band	3842	11	5674	13	854	22	1.24 (0.75–2.05)
Majority work 8 band	1062	3	1353	3	386	10	0.99 (0.31–3.12)

Table 2 (*Continued*)

	At what point was patient assessed (n = 80,113)						Adjusted Relative risk ratio[a]
	After diagnosis n = (34149)	%	Before/at diagnosis n = (42155)	%	Missing n = (3809)	%	Before/at diagnosis vs After diagnosis
LCNS Band							
All 7 band	16,442	48	17,775	42	1296	34	1
6,7 & 8 Bands	15,121	44	18664	44	2023	53	1.17 (0.82–1.66)
7,8 Bands	2586	8	5716	14	490	13	2.09 (1.18 –3.71)

Baseline group patients assessed after diagnosis.

[a] Relative risk ratio adjusted for Trust/LCNS feature, year and patient features.

[b] Significant p value for trends/likelihood ratio test ($p < 0.05$).

[c] Not Adjusted for other LCNS Band Variable.

Table 3
Multinomial logistic regression analysis for patient features and where the patient was first assessed by a LCNS clustered by NHS Trust (n = 80,113).

	Where was the patient first assessed (n = 80,113)								Adjusted Relative risk ratio[a]	
	In Clinic n = (49065)	%	In Ward n = (15792)	%	Others (inc tele/home) n = (6939)	%	Missing n = (8317)	%	In Ward vs In Clinic	Other vs In Clinic
Year										
2007	3114	6	1074	7	667	10	1361	16	1[b]	1[b]
2008	7111	14	2527	16	788	11	1809	22	1.00 (0.82–1.21)	0.49 (0.30–0.81)
2009	11,216	23	3485	23	1450	21	1325	16	0.95 (0.75–1.20)	0.60 (0.36–0.99)
2010	13,316	27	4074	26	2019	29	1532	18	0.86 (0.70–1.06)	0.73 (0.44–1.22)
2011	14,308	29	4432	28	2015	29	2290	28	0.89 (0.70–1.13)	0.68 (0.42–1.11)
Sex										
Female	21,301	43	7149	45	3136	45	3683	44	1[b]	1
Male	27,764	57	8643	55	3803	55	4634	56	0.91 (0.87–0.95)	0.91 (0.87–0.96)
Age										
< 65	13,644	28	3874	25	1969	28	2228	27	1	1
65–75	17,071	35	4851	31	2392	34	2804	34	0.85 (0.81–0.90)	0.92 (0.86–1.00)
> 75	18,350	37	7067	45	2578	37	3285	39	0.81 (0.75–0.87)	0.86 (0.79–0.94)
Performance status										
0	10,651	22	1060	7	1235	18	1372	16	1[b]	1
1	17,356	35	2911	18	2322	33	2148	26	1.30 (1.12–1.49)	1.16 (0.98–1.36)
2	9414	19	3418	22	1231	18	1378	17	1.96 (1.67–2.29)	1.12 (0.96–1.32)
3	5506	11	4730	30	819	12	1199	14	3.36 (2.81–4.02)	1.26 (1.04–1.52)
4	758	2	1853	12	177	3	310	4	7.22 (5.75–9.07)	1.94 (1.42–2.64)
Missing	5380	11	1820	12	1155	17	1910	23	1.87 (1.56–2.24)	1.66 (1.35–2.06)
Stage										
IA-IB	6192	13	681	4	961	14	945	11	1[b]	1
IIA-IIB	3319	7	478	3	444	6	451	5	1.32 (1.13–1.54)	0.86 (0.75–1.00)
IIIA	5318	11	885	6	671	10	716	9	1.43 (1.25–1.64)	0.81 (0.70–0.94)
IIIB	6133	12	1548	10	791	11	850	10	1.97 (1.73–2.25)	0.85 (0.73–0.98)
IV	16,611	34	7896	50	2284	33	2688	32	2.33 (2.04–2.67)	0.83 (0.72–0.95)
SCLC-Limited	2000	4	413	3	253	4	267	3	2.15 (1.81–2.55)	0.83 (0.71–0.98)
SCLC-Extensive	3283	7	1609	10	428	6	472	6	2.84 (2.40–3.35)	0.80 (0.68–0.95)
Stage Unknown	6209	13	2282	14	1107	16	1928	23	2.10 (1.79–2.45)	1.00 (0.79–1.27)
Charlson Index										
0	18,384	37	2668	17	2289	33	2791	34	1[b]	1
1	10,647	22	2381	15	1493	22	1641	20	1.21 (1.12–1.30)	1.10 (1.01–1.21)
2–3	8940	18	2293	15	1252	18	1407	17	1.18 (1.09–1.29)	1.10 (1.00–1.20)
4+	11094	23	8450	54	1905	27	2478	30	2.46 (2.27–2.66)	1.32 (1.18–1.46)
Townsend Quintile										
1 (Most affluent)	7611	16	2258	14	1263	18	1121	13	1	1
2	8972	18	2678	17	1458	21	1398	17	1.00 (0.92–1.09)	0.99 (0.89–1.11)
3	9696	20	2989	19	1486	21	1499	18	0.99 (0.90–1.08)	0.94 (0.83–1.07)
4	10,462	21	3396	21	1376	20	1744	21	0.96 (0.86–1.06)	0.81 (0.69–0.95)
5 (Least affluent)	11,548	24	4014	25	1244	18	2434	29	0.97 (0.85–1.11)	0.67 (0.54–0.85)
Missing	776	2	457	3	112	2	121	1	1.30 (1.09–1.56)	0.81 (0.63–1.05)
Route of Referral										
Referred from GP	29257	60	3272	21	3845	55	4035	49	1[b]	1
pEmergency Admission	3050	6	5073	32	682	10	663	8	8.48 (6.65–10.8)	1.52 (1.22–1.88)
Referred from Consultant	9961	20	3679	23	1438	21	1475	18	2.51 (2.12–2.97)	1.03 (0.89–1.19)

Table 3 (*Continued*)

	Where was the patient first assessed (n = 80,113)								Adjusted Relative risk ratio[a]	
	In Clinic n = (49065)	%	In Ward n = (15792)	%	Others (inc tele/home) n = (6939)	%	Missing n = (8317)	%	In Ward vs In Clinic	Other vs In Clinic
pFollowing A&E admission	1991	4	2427	15	382	6	510	6	6.72 (5.50–8.20)	1.41 (1.14–1.74)
Others	3401	7	945	6	357	5	603	7	2.01 (1.54–2.63)	0.74 (0.50–1.09)
Missing	1405	3	396	3	235	3	1031	12	2.07 (1.29–3.31)	1.32 (0.79–2.23)
Treatment										
No treatment	13,295	27	8997	57	2017	29	2896	35	1[b]	1
Surgery	8285	17	769	5	1223	18	1338	16	0.48 (0.42–0.57)	1.05 (0.90–1.22)
Chemo & radiotherapy	6728	14	1131	7	913	13	854	10	0.47 (0.41–0.55)	1.00 (0.83–1.19)
Chemo Only	11,669	24	2285	14	1466	21	1671	20	0.51 (0.45–0.57)	0.90 (0.79–1.03)
Radiotherapy only	9088	19	2610	17	1320	19	1558	19	0.64 (0.58–0.70)	1.03 (0.92–1.14)
Trust Size (Annual)										
<175 pts	19,117	39	6840	43	2873	41	1935	23	1[b]	1
>=175 – <265 pts	15,683	32	5307	34	2788	40	2729	33	0.96 (0.76–1.21)	1.20 (0.75–1.92)
>=265 pts	14,265	29	3645	23	1278	18	3653	44	0.76 (0.58–1.00)	0.61 (0.40–0.94)
Caseload										
<=150 cases	11,557	24	4313	27	1507	22	1296	16	1	1
>150 – <=250 cases	25,667	52	7518	48	3899	56	6413	77	0.88 (0.69–1.13)	1.09 (0.68–1.73)
>250 cases	11,841	24	3961	25	1533	22	608	7	1.03 (0.75–1.42)	0.90 (0.51–1.57)
LCNS dealing with > 50% work[c]										
Majority work 7 band	42,443	87	13,476	85	6148	89	4875	59	1	1
Majority work 6 band	5130	10	1791	11	608	9	2841	34	1.30 (0.87–1.94)	0.97 (0.49–1.92)
Majority work 8 band	1492	3	525	3	183	3	601	7	1.04 (0.80–1.35)	0.80 (0.41–1.55)
LCNS Band										
All 7 band	22,527	46	7643	48	3330	48	2013	24	1	1
6,7 & 8 Bands	21,097	43	6417	41	3065	44	5229	63	0.90 (0.72–1.14)	0.96 (0.61–1.53)
7,8 Bands	5441	11	1732	11	544	8	1075	13	0.95 (0.74–1.22)	0.69 (0.41–1.15)

Baseline group patients assessed in clinic.

[a] Relative risk ratio adjusted for Trust/LCNS feature, year and patient features.

[b] Significant p value for trends/likelihood ratio test ($p < 0.05$).

[c] Not Adjusted for other LCNS Band Variable.

WTE LCNS on the likelihood of being assessed was not present even when adjusted for several patient and Trust features. This may be due to differences in access to a LCNS, which were not examined in this study.

This study uses a large representative dataset reflects real life LC care in England. Although the data entry in the NLCA is non-mandatory, the linked database has been validated [16]. The ascertainment of cases and data completeness has improved annually with recent audit result reports ascertainment closer to 100% [17]. We had a large proportion of patients with missing data on LCNS input; but the decreasing missing information in recent years associated with no change in the proportion of assessed vs not assessed in the database suggests that this was not deliberate (Supplemental Table 2). This is the first time a snapshot of the LCNS workforce together with the patient level data was used to create an approximate patient caseload per WTE LCNS. Although we used the most recent data from the NCAT, the number of employed LCNS has remained relatively stable since 2007 (301 total LCNS in 2010 & 321 in 2011). Our results could be influenced by bias as patients with aggressive disease and short survival time may not have the opportunity to be assessed, however we conducted a sensitivity analysis limiting to all those patients who have survived for more than 30 days after diagnosis and observed the same association (Supplemental Table 1). It could be argued for some patients opting for palliative treatment, a palliative care specialist nurse would be more effective at attending to patient's needs, but we believe that the skills and expertise of the LCNS are complementary and should still be available.

We created two variables to measure the effectiveness of LCNS based on their salary grade and the amount of work performed by them and observed a relationship of patients being assessed more and before diagnosis with Trusts where more senior nurses on higher salary bands are hired. With recent downgrading of nurses to band 6, our study highlights evidence of hiring more experienced nurses. It is very likely that many patients during the course of their treatment change nurses (for e.g. from LCNS to specialist oncology nurse) and not all patients visit a LCNS each year survived after their diagnosis, however we believe that the number would be sufficiently small because of the poor survival rates [18] of LC and majority of the caseload for each LCNS comprised of new patients. Additionally, the surviving patients can still contact or can be referred to a LCNS from other CNSs.

We assumed that being assessed in a clinic represented best practice as it signified patients contact with the LCNS during the initial LC pathways. This may not be the true for patients suffering from aggressive LC where they are first presented in emergency rather than visit to their GP. This would not make much difference as only 13% of the total LC population are referred to a lung physician in emergency, while around 50% are referred from GPs and other consultants [14,19,20].

The NICE guidelines have stated that every patient diagnosed with LC should have an access to a LCNS [1] while the NLCA audit suggesting that 80% of patients in each Trust should be assessed by a LCNS [12] and our results do provide evidence that most Trusts are now achieving this benchmark. In addition, there is also the presence of variation in caseload per WTE LCNS which is also observed in the NLCA annual audit reports [12,17].

We used a combination of database and survey to plot LCNS activities in NHS Trusts in England, and found that contact with LCNS was associated with increased likelihood of having received chemotherapy, radiotherapy and surgery. These results, except for surgery, are similar to results presented by Beckett et al. [4] who analysed patients in the NLCA in 2009. However, due to the retrospective analysis nature of the study and limited data on determining at which point in the LC pathway these patients were assessed, it is difficult to establish temporal relationship between being assessed and receiving anti-cancer therapy. Our results indicate that Trusts with low annual patient Trust size or with low per WTE LCNS caseload were more likely to assess patients which is similar to the Royal College of Physicians report [21], which found that multidisciplinary teams with low caseload per LCNS more likely to meet targets for outcomes.

5. Conclusion

LCNS provide a valued service for patients suffering from LC however we found wide variations between patient features, annual Trust workload, LCNS caseload and who are assessed by a LCNS in between Trusts across England suggesting an unmet need of some patients with LC. To meet the needs of all people with LC and the clear targets set out by NICE, we need to expand the current LCNS workforce and ensure that we retain experienced nurses as LCNS are an integral part of the LC team and provide help to people with LC.

Conflict of interest

PB, AT, AL, DB & JW have no conflict of interest. LJT has conducted the statistical analyses for the National Lung Cancer Audit annual reports from 2009 to 2013, which was funded by the NHS Information Centre, while AK has been involved in audit analysis for past 2 year including analysis for this year. LJT and AK have not received any personal earnings from the NHS HSCIC for this work. RBH has a grant provided by the British Lung Foundation chair of respiratory epidemiology. RAS was employed by the HSCIC as the Project Manager for the NLCA database until October 2013.

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Appendix A. Supplementary data

Supplementary data associated with this article can be found, in the online version, at http://dx.doi.org/10.1016/j.lungcan.2016.03.011.

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